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Personal transformation in chronic physical disease: conceptual limitations of the posttraumatic growth construct

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This quantitative-qualitative case study focuses on processes of personal transformation in chronic physical disease in order to further our understanding of the posttraumatic growth construct. Semistructured interviews were conducted with women suffering from Systemic Lupus Erythematosus. The validity of the posttraumatic growth construct is assessed comparing results obtained by a standardized measure (Posttraumatic Growth Inventory) to individual pictorial and verbal depictions of personal transformation processes. Detailed examinations of three cases evidenced the validity of subjective appraisals of posttraumatic growth. Also, the Posttraumatic Growth Inventory covered all facets of positive growth processes as portrayed by individual depictions. However, the concept of posttraumatic growth neglects negatively evaluated processes of personal transformation. The consequences of this conceptual bias are discussed with respect to clinical care as well as contradictory results seen in empirical research. Posttraumatic loss and destruction is suggested as a second dimension for the representation of personal transformation in chronic physical disease.

Key words: *Personal transformation; Posttraumatic Growth; Chronic physical disease; Systemic Lupus Erythematosus*

Even before the introduction of posttraumatic stress disorder (PTSD) as a diagnosis in DSM-III (APA, 1980), it was recognized that trauma survivors experience changes beyond psychopathological developments. For instance, the psychoanalyst Rangell (1967, p. 77, original emphasis) noted that "trauma may lead not only to pathogenesis but also to *higher* levels of adaptation". Current concepts of posttraumatic growth (PG) reflect subjectively perceived positive changes in the aftermath of a traumatic event including aspects as the detection of personal strength, changes in attitudes towards life, improved social relations, appreciation of life, and spiritual changes. According to Tedeschi, Park, and

Calhoun (1998) posttraumatic growth can be considered a process as well as an outcome. They compare the underlying psychological processes with a community struck by an earthquake. After a period of confusion and mourning the reconstruction is initiated. This may not only result in stronger structures but also allow for the experience of mutual support among the community members. However, PG has not only been found after seismic (i.e., traumatic) events, but also in individuals with (chronic) physical disease as cancer, HIV infection, or heart attacks (Tedeschi et al., 1998). With the availability of reliable self-rating instruments (Park, Cohen, & Murch, 1996; Tedeschi & Calhoun, 1996), a growing number of publications have reflected interest in the consequences of adverse events other than psychopathology. Accordingly, Morris, Shakespeare-Finch, Rieck, and Newbery (2005) recognized “a philosophical shift from a pathogenic to a salutogenic paradigm”.

Research regarding the relationship between PG and (posttraumatic) stress has yielded contradictory results. Weinrib, Rothrock, Johnsen, and Lutgendorf (2006) summarized studies reporting linear positive, negative, or no correlations between PG and stress measures. Kleim and Ehlers (2009) reported evidence for a curvilinear relationship between PG and PTSD symptom severity. Finally, the meta-analysis by Helgeson, Reynolds, and Tomich (2006) identified the time elapsed since a stressful event as a factor influencing their relationship.

Unfortunately, the construct of posttraumatic growth does not appear to be sufficiently related to personality theory. Although the concept of PG describes how growth is recognized, it does not offer a clear concept or tools for the assessment of those personality dimensions in which growth occurs. Tennen and Affleck (1998) distinguished between personality constructs reflecting dispositional traits, personal concerns, and life narratives (level of identity). They assumed that PG relates to the latter two dimensions. Similarly, Sumalla, Ochoa, and Blanco (2009) labelled PG in cancer patients as positive identity changes. However, without a thorough understanding of baseline conditions (i.e., personality before a traumatic event or illness onset), it is hard to understand the effect of any event on these conditions. As a result, several unresolved issues arise. First, it is not sufficiently clear whether subjective appraisals of PG reflect genuine growth processes or rather “illusionary aspects” (Zoellner & Maercker, 2006) due to a tendency to positively biased self perception. Second, without a comparison of baseline and post-growth conditions, it is difficult to understand whether current measures of PG cover all central dimensions of growth processes. Finally, as noted by Schok, Kleber, Elands, and Weerts (2008), the concept of PG limits processes of personal transformation after adverse events to positive changes. Contrarily, Schok et al. concluded from their review of appraisals of military deployment experiences among veterans that positive and negative dimensions are independently present at the same time. To date only little work has been done to identify negative valued long-term personality processes after trauma. One recent exception is the introduction of the concept of Posttraumatic

Embitterment Disorder (PTED) by Linden (2003). PTED is characterized by long term embitterment and emotional arousal caused by a violation of basic beliefs and values triggered by an exceptional, negative life event.

Without a thorough understanding of all facets of processes of personal transformation, transfer of the yet contradictory results of empirical research to clinical applications in psychotherapy remains hampered. Therefore, this study aims at improving our understanding of processes of personal transformation in chronic physical disease by questioning the construct of PG as measured by the PGI with respect to possible illusionary aspects in subjective appraisals of posttraumatic growth, coverage of observable growth processes by this construct, and consequences of limiting this construct to positive changes.

Method

This study was approved by the appropriate Institutional Review Board.

We performed a quantitative-qualitative case study on the relationship of suffering and PG in twelve women with chronic physical disease (systemic lupus erythematosus, SLE; Wittmann, Sensky, Meder, Michel, Stoll, & Buechi, 2009). SLE is a chronic relapsing autoimmune disorder which predominantly affects young women. It can involve most organ systems, interferes with social role function and can have marked effects on life expectancy (Ward, Pyun, & Studenski, 1995). PG was assessed by the Posttraumatic Growth Inventory (PGI, Tedeschi & Calhoun, 1996). As outlined in the introduction, Tennen and Affleck (1998) assume that growth processes occur within the dimensions of personal concerns and the level of identity related to life narratives. In order to reflect these aspects in a broad and individual approach, Cassel's (1982) definition of a person was applied. According to Cassel, a simplified description of a person comprises dimensions as relationships with others, the range of activities, life experiences, the body, and aspects of transcendence. Thus, detailed individual depictions of the person before disease onset and changes to this picture due to the illness were obtained (see section measures).

Participants: We present three cases of women suffering from SLE. Following a purposive sampling strategy, the three cases were chosen from a larger sample ($n = 12$; Wittmann et al., 2009) in order to represent three different levels of (low, medium, and high) PG. All three subjects were diagnosed with SLE according to classification criteria of the American Rheumatology Association (Tan et al., 1982).

Procedure: Participants were asked to participate during a meeting of a Swiss SLE patient's organization. Information about the study was provided and participants gave written informed consent. After an extensive interview they completed a questionnaire and participated in a rheumatologic examination assessing standard parameters of SLE diagnosis (Gladman et al., 1996; Gladman et al., 1997; Hay et al., 1993; Stoll, Stucki, Malik, Pyke, & Isenberg, 1996).

Measures:

Interview. Semi-structured interviews were audio taped. The first part of the interview focused on the illness and changes experienced due to it. If not mentioned spontaneously, participants were asked if they had noticed any change regarding the areas of health, social-, professional-, and emotional life, self-perception, life goals, and spirituality. As the second part of the interview focused on the experience of suffering and its relation to the illness, it is not described here. Altogether, interviews lasted about 90 minutes.

Assessment of the person. After the interviews participants retrospectively depicted the most relevant aspects of their person before illness onset by the Pictorial Representation of Illness and Self Measure+ (PRISM+, Büchi & Sensky, 1999) and then indicated how this picture had changed due to the illness. PRISM+ consists of a white A4-sized metal board with a fixed yellow circle 7 cm in diameter at the bottom right-hand corner. Subjects are handed coloured detachable disks representing any dimension of their person they consider important. Subjects attach these discs to the board. They are told that the closer they put a disk to the yellow circle, the more essential the respective dimension is to the person relative to other dimensions.

Posttraumatic Growth. Finally, participants completed the Posttraumatic Growth Inventory (PGI, Tedeschi & Calhoun, 1996), consisting of 21-items. A total score and five subscales (Appreciation of Life, Personal Strength, Relating to Others, New Possibilities, Spiritual Change) can be computed. We applied the reliable and validated German version (Maercker & Langner, 2001). The questionnaire instructions were adapted to the circumstances of SLE-patients. As the German version applies a Likert scale ranging from 0 “not at all” and 1 “somewhat” to 2 “very strong”, comparison with results from international studies applying the original 5-point Likert scale is impeded. Therefore, we show all values including the possible maximum value as well as values from the sample of the German validation study (Maercker & Langner, 2001). This sample consisted of 82 university students after severe life experiences and 59 clinic (internal medicine) patients.

Data analysis: After transcription of interview records according to an adaptation of international criteria (Mergenthaler & Stinson, 1992) summarizing content-analysis (Flick, 2006; Mayring, 2002) based on the software ATLAS.ti, 5.1 was applied to texts. A categorization system comprising four categories (“changes due to the illness”, “causes of suffering”, “quality of suffering”, and “coping with suffering”) was developed. After a training of the application of the categorization system, both investigators independently identified quotations (69% agreement) and assigned categories to quotations (interrater reliability $\kappa = .79$) for three interviews (out of the twelve interviews of the overall sample). Remaining interviews were analyzed by the first investigator. For the following case reports (section Results), only quotations of the category “changes due to the illness” were considered. Changes as illustrated by quotations (interview) or pictorial representations (PRISM+) are then compared to processes of personal transformation as detected by the PGI.

Results

1. Mrs. U

Although retired, 67-year-old Mrs. U. still works as a freelancer in the area of cultural history for her former employer, a well-known publishing house. She described herself before the onset of her illness (about 35 years before the interview) as dominated by two domains (fig. 1a): her family (husband and children) and knowledge, the latter strongly related to her profession.

SLE struck her with many typical symptoms such as sensitivity to sunlight, pain, problems with digestion, fatigue, and loss of hair. However, after a long and severe life crisis she was able to use her willpower and her social network to adapt to the conditions of life with SLE. Although she did not need to change the first PRISM+ picture in order to reflect her current person (fig. 1b), the definitions of the two discs appear to have been broadened. Explaining the

disc labelled “family” Mrs. U. mentions that she had started to take care of her grandchildren. It was also important for her to tell them everything about their family history. “[...] yes, my grandchildren, this is very important, that I spend much time with them. That they know who I am” (own translation).

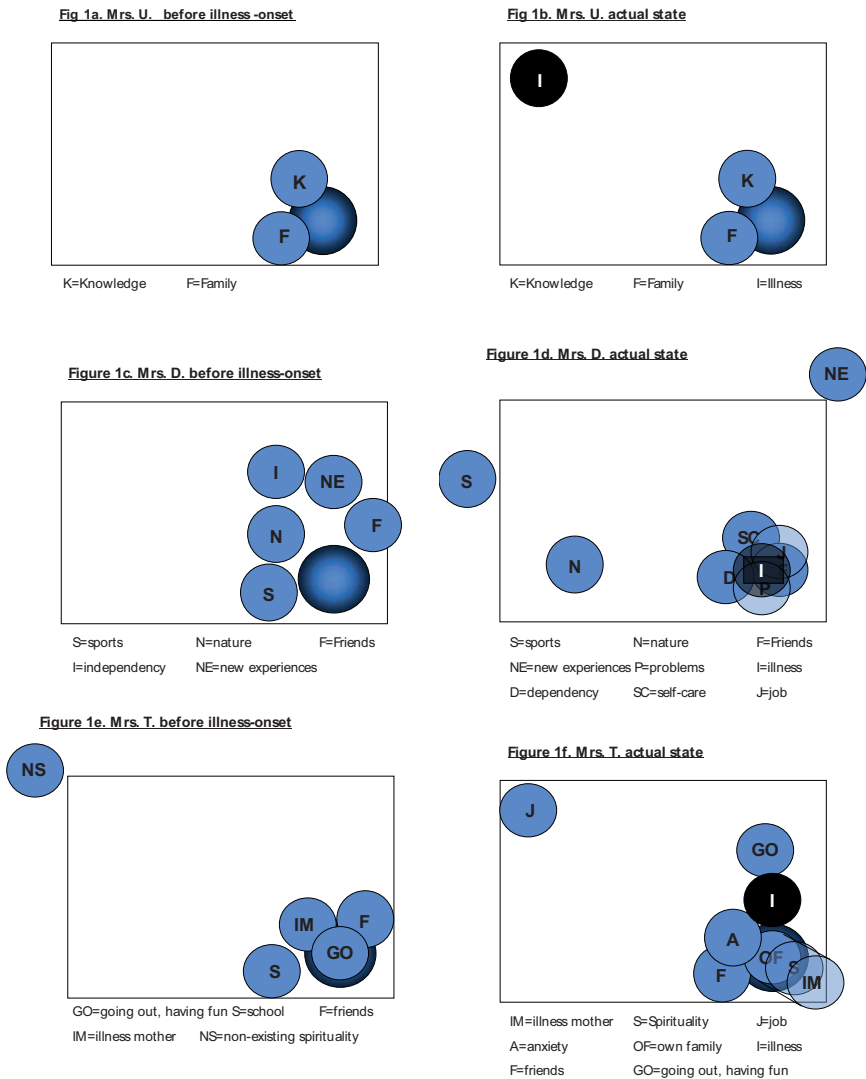


Figure 1. Representations of participant’s persons before illness onset and changes caused by the illness. Reprinted with permission from Psychosomatics, (Copyright 2009). American Psychiatric Publishing, Inc.

As for the “knowledge” disc, it now represented knowledge in a broader sense, more spiritual than professional, and knowledge about the roots of her family: “Knowledge is still there. But knowledge in another way. [...] It’s more about spirituality, not completely, but almost. And I became strongly interested in my origin. Before, I was not. [...] my father wanted to tell me a lot about it, but I was not really interested in. And now it is almost the opposite, I know almost as much as he did. [...] I want to watch back on fathers and grandfathers side until 1500” (own translation). According to the PGI (fig. 2), Mrs. U. was rather similar to values from the validation sample in all dimensions.

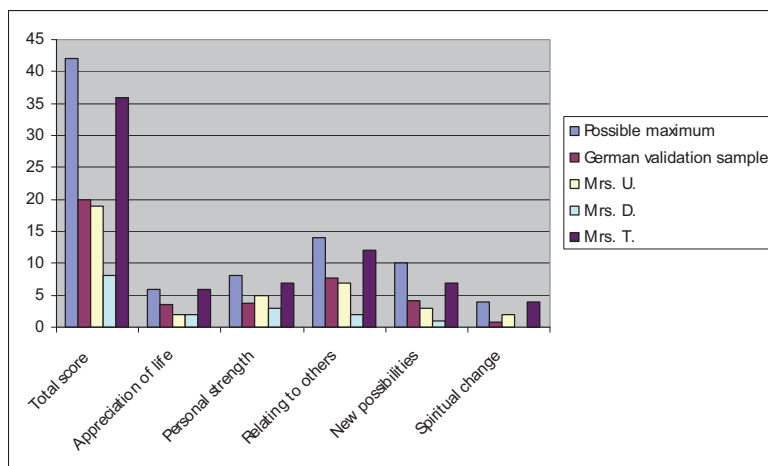


Figure 2. Posttraumatic Growth Inventory total and subscale scores of the three participants as well as values from the German validation sample

A closer look at the PGI at the item level revealed that Mrs. U. had the highest ratings (“very strong”) on items 5 (“I have a better understanding of spiritual matters”), 8 (“I have a greater sense of closeness with others”), and 12 (“I am better able to accept the way things work out”).

Mrs. U.: Comparison of qualitative data and PGI scores

The integration of her illness did not cause Mrs. U. to change her PRISM+ picture. However, she broadened the definitions of her two discs: she developed a more intense relationship with her grandchildren and felt that they – as herself – were links in the same chain and began to introduce them to their family history. Also, her pursuit of knowledge became enriched by a spiritual dimension. From the interview we also know that her willpower and social network helped her overcome the severe crisis due to SLE. These observations are in line with results from the PGI which revealed high ratings on items representing spiritual matters, closeness with others, and personal strengths.

2. Mrs. D

Today, Mrs. D. is 35 years old and works part-time as an occupational therapist. As can be seen from Figure 1c, she describes herself before illness-onset (about 9 years ago) as an open and independent person, enjoying sports, nature, and socializing with her friends. Among her worst SLE symptoms are pain, fatigue, a severe sensitivity to light as well as hair loss. Despite her young age she is partially unable to work and is afraid to lose her ability to work completely. Many friendships which were related to shared activities were lost and she will not be able to realize her most important life plan of having her own children. Figure 1d reflects the vast destruction of many parts of her former self. Several aspects are intermingled with discs representing problems and illness. Sports, nature, new experiences, or friends no longer have a place in her life or are negatively evaluated in comparison to their former qualities. What she had proudly called her independence has turned into its opposite. Although some friends have remained, she feels isolated and resigned. The only positive changes she attributes to her illness are that she feels more self-aware, self-assured, and empathetic than before: "There are parts of myself where I have more self-confidence, that I feel more self-assured. [...] I would say I feel myself more as a person than I did before. [...] One becomes more empathetic, maybe, towards the suffering of other people" (own translation). As far as Mrs. D. is concerned, SLE is a wild animal trying to destroy her. As obvious from Figure 2, Mrs. D obtained very low scores on most subscales of the PTGI. Only item 1 ("I changed my priorities about what is important in life") was rated with "very strong". Six more items were rated with "somewhat", three of them referring to personal strengths (items 4 "I have a greater feeling of self-reliance", 12 "I am better able to accept the way things work out", and 19 "I discovered that I'm stronger than I thought I was"). Similarly, item 15 ("I have more compassion for others") was rated with "somewhat".

Mrs. D.: Comparison of qualitative data and PGI scores

The profound changes due to SLE in Mrs. D.'s PRISM+ picture can best be described as a pile of shards of her former self without the formation of a new consistent picture. Nevertheless, the few positive changes mentioned in the interview (feeling more self-aware, self-assured, and empathetic) appear to be reflected by the PGI subscale "Personal strength" score with elevated ratings on the items concerning greater self-reliance (item 4), being stronger (item 19), and having more compassion for others (item 15).

3. Mrs. T

Today, Mrs. T. is 30 years old and lives with her husband and two children in the countryside. She described herself in the time before her illness, which began at the end of high school, in typical schoolgirl fashion as going out with friends and having fun (fig. 1e). However, her mother's severe illness (progressive cancer) necessitated her taking over a great deal of responsibility

for her mother and two younger sisters. Interestingly, she insisted upon adding a disc which she labelled “not yet existing spirituality” to this depiction, however, only outside of the space provided for describing herself. SLE has inflicted her with a number of symptoms. She developed sensitivity to sunlight as well as kidney and pulmonary problems. As a young woman she also suffered from a significant loss of hair. Her belief in herself was also affected. She had to replace her conception of being a mature person without problems by recognizing her own needs and dependency on others. The prospect that her remaining life span was limited caused changes to her appraisals of what was important in life. She stopped working and began a family with her boyfriend. Also, she re-evaluated her social contacts in order to continue only those that were essential to her: “There have been large changes regarding my family and my friends, I mean, somehow I became more conscious about who is really close to me and what is important in life. I left many superficial things behind, as I didn’t need them any more [...]” (own translation). Having felt the fleeting nature of life, she now considers life a precious gift and feels stronger and calmer than before: “For me, the meaning [of the illness] was that I found myself, well, somehow I stopped being so wild, I became more calm, and started to open myself for spiritual and esoteric aspects [...]. Now I know that I am stronger than I always assumed” (own translation). From her description of her current self (fig. 1f), a number of changes are obvious. The illness and related anxiety have become an important aspect of herself. Many of her symptoms are hard for her to accept. The school disc, which was replaced by a job disc, is granted only a rather distant position. Also, going out and having fun is much less important. The most dominant change, however, is her spirituality which floats centrally above the other domains: “Because it somehow is always present and it protects me” (own translation). Another disc floating above the scene is the memory of her mother’s illness. This acts as a constant warning for Mrs. T. to not make the same mistakes her mother made and not let her illness destroy her life. In all dimensions of the PGI (fig. 2) Mrs. T. reaches values close to the possible maximum scores and far above values from the validation sample. The only item rated with “not at all” was item 14 (“New opportunities are available which wouldn’t have been otherwise”), however, three of the four remaining items in the subscale “New possibilities” were rated with “very strong”.

Mrs. T.: Comparison of qualitative data and PGI scores

The many transformations due to SLE which are obvious from Mrs. T.’s PRISM+ and interview data resulted in a coherent and enriched new picture. Whereas some aspects have lost their meaning (school / job), others appear to dominate the new picture (spirituality). Others again have changed their meaning: whereas her mother’s illness was like a shadow over her youth, it now is a central motive to do better and not let her own illness destroy her life. Negative experiences such as anxiety and typical SLE symptoms have not hindered Mrs.

T. from appreciating life. The many changes described by PRISM+ and interview statements are reflected in elevated PGI scores on all subscales.

DISCUSSION

The presented results are not without limitations. Depictions of the participants' earlier selves were made retrospectively over many years and could have been biased by recall deficits or their current condition. However, the obtained descriptions gave the impression of traceable and rather balanced evaluations. The three presented cases – women with chronic physical disease – represent a highly selective sample and results require replication in other groups of persons suffering from physical disease or traumatic events. Generally, qualitative analyses are considered to suffer from low objectivity. Given the high degree of interrater-reliability of our analyses and that the presented data is largely confined to citations from our participants, the potential degree of interpretational bias appears to be limited. Of course, an ideographic approach based on a sample of three cases can never reveal universally valid results. Rather, the strength of our approach lies in a level of illustration of abstract constructs and their relationships that cannot be obtained by standardized measures. From this richness of details hypotheses can be derived which need to be tested in larger samples.

Illusionary aspects in subjective appraisals of posttraumatic growth

Due to the purposive sampling, degrees of PG as measured by PGI differed in our three cases. PG was virtually absent in the case of Mrs. D. On the other hand, Mrs. U. showed an average level of PG, and Mrs. T. scored close to the possible maximum values. PGI dimensions and items with elevated scores corresponded to information from the qualitative data. Given the extreme scores obtained in the PGI, Mrs. T. would be the most suspect case for illusionary aspects in growth ratings. However, for all dimensions of the PGI, convincing examples were reflected by PRISM+ and interview data. She stated that the enhanced awareness of the transitory nature of life made her consider life a precious gift (Appreciation of life). She described herself as stronger and calmer (Personal strength). The illness led her to continue only essential relationships (Relating to others). Based on the knowledge about her development from qualitative data (i.e., her decision to found a family rather than pursuing a professional career), high ratings in the PGI dimension of new possibilities (items referring to establishing a new path for life or being able to do better things with life) are understandable, too. The dramatic change depicted by PRISM+ from non-existing spirituality to a spirituality dominating the whole depiction of her person corresponds closely with the high rating in the spirituality dimension of

the PGI. A further argument against dominant illusionary processes is that Mrs. T. did not deny psychopathological symptoms (anxiety) or negative personal transformation in the domain of personal strength (recognizing her dependency on others; feeling less attractive due to hair loss).

Summarizing, individual scores in PGI subscales were confirmed by results obtained through a different assessment method. Depicting the person before illness onset and then illustrating and explaining changes to this picture due to the illness yielded convincing and traceable confirmation of growth processes as measured by the PGI. As far as can be judged from the overall impressions gathered in a very personal interview of 90 minutes duration, there were no hints of illusionary, contradictory, or superficial aspects in the judgements of growth processes. This validation of the authenticity of growth processes is in line with results from another study comparing reports of growth obtained by the PGI and essays on the impact of stressful events (Weinrib et al., 2006). Further studies comparing PG from participants' self-ratings with ratings obtained from informants (Park et al., 1996; Weiss, 2002) have provided additional confirmatory evidence.

Conceptual amplitude of the posttraumatic growth construct

The sections "Comparison of qualitative data and PGI scores" within the case reports already showed that depictions and statements of positively evaluated processes of personal transformation obvious from qualitative data were reflected by elevated scores on related PGI items / dimensions. We did not find any statement regarding positive growth processes which indicated a dimension not sufficiently covered by the concept of posttraumatic growth as measured by the PGI. Thus, the conceptual amplitude of the construct appears to be convincing.

Possible consequences of limiting this construct to positive changes

The concept of posttraumatic growth aims to consider a broader perspective than just psychopathology by covering positively evaluated personal transformations. However, comparison of depictions of individuals before illness onset and changes to these pictures caused by the illness also make clear that personal transformation is not limited to positive identity changes. All three cases presented negative personal transformations as well. For instance, all participants were limited due to their illness in the range of activities that were once important to them. Such changes could be summarized along a dimension comprising loss of possibilities as opposed to new possibilities. Negative personal transformation was especially obvious in the case of Mrs. D. whose PRISM+ illustration represented a vast destruction of her former self without substantial restoration. For instance, previously important interests, such as sports or having new experiences, have been thrown out of the picture without being replaced by other positively evaluated aspects. This severe situation was not adequately

reflected by the absence of growth in the PGI. Absence of growth would describe an unchanged picture, but does not depict the vast destruction obvious from the qualitative data. Even Mrs. T., who presented the most pronounced growth in all dimensions, reported negative personal transformations, especially in the area of personal strength (depending on others), but also regarding the range of formerly enjoyed activities. Thus, the presence of positive growth does not exclude the presence of negative transformations, and even a vast personal destruction does not rule out the possibility of positive growth processes. This is in line with Schok et al.'s (2008) assumption of a mutual independence of positive and negative personal transformations.

As summarized in the introduction, studies of the relationship between posttraumatic growth and psychopathology have yielded differing results. Considering positive as well as negative responses, Joseph, Williams, and Yule (1993) found that negative changes were more strongly related to psychopathology than positive ones. Similarly, Spiro, Schnurr, and Aldwin (1997) reported that positive and negative appraisals of military service were independently related to psychopathology. We assume that an understanding of the relationship between personal transformation and psychopathology requires augmentation of the posttraumatic growth construct by a dimension of stress-related loss and destruction. Posttraumatic Embitterment Disorder (PTED) covers one facet of this, but is limited to a violation of a person's basic beliefs or values (Linden, 2003). It is important to mention that, in contrast to our understanding of negative changes beyond psychopathology, PTED is conceptualized as an adjustment disorder. ICD-10 (Dilling, Mombour, & Schmidt, 1991) diagnosis of enduring personality changes after catastrophic experience (F62.0) emphasizes interpersonal changes as mistrust or social withdrawal. In developing a new measure, one would need to take care not to confound items with aspects of psychopathology. In operationalizing such a dimension of loss and destruction, one should consider facets such as devaluation of life, personal weakness, disappointment about or isolation from others, restriction of enjoyed activities, and loss of faith or basic beliefs. We do not understand the suggested completion of posttraumatic growth as turning away from a salutogenic paradigm. Rather, we believe that only a balanced perception of all processes of personal transformation after traumatic events may represent authentic rather than illusory growth processes.

This perspective also has important clinical implications applicable to many settings ranging from nursing or rehabilitation (chronic physical disease, handicapping injuries) to psychotherapy (chronic psychic illness or traumatisations). To accompany patients working through the consequences of injuries / physical disease, mental illness or stressful events we need to consider the whole range of related personal transformations beyond psychopathology. If we limit this work to positive changes, we are in danger of missing the phenomenological reality of heavily burdened patients and eventually of leaving them alone in their struggle.

Schok et al. (2008, p. 364) assumed “[...] that the balance between positive and negative appraisals is critical in order to integrate the reality of the experience and to provide a context for personal growth”. Implementing a construct of personal transformation after stressful events with dimensions of positive and negative identity changes will bring us one step further towards an understanding of the interaction of (traumatic) stress and personality.

A final comment pertains to the term growth and the evaluation of changes as positive or negative. The PGI considers a high rating on the item “I learned a great deal about how wonderful people are” as indicating posttraumatic growth. Could not a low rating after man-made trauma reflect the correction of former illusions about human nature and indicate a real growth process in the sense of “sadder but wiser” (Alloy & Abramson, 1979)? Also we need to be aware of the fundamental judgement inherent in the definition of growth processes. While some individuals may consider a growing spirituality as a positive change, others may consider it a step into psychic dependency. A new measure of processes of personal change after adverse events should permit individual subjective ratings of changes as positive or negative rather than supporting a normative definition of positive trauma outcomes.

CONCLUSION

This study shows how contrasting a quantitative measure of posttraumatic growth with an ideographic approach of data collection can deepen our understanding of processes of personal transformation and illustrate conceptual shortcomings of this instrument. We propose the development of a measure of personal transformation that considers positive and negative outcomes but avoids normative evaluations of these changes. Future research needs to show if such a construct will help to explain conflicting research results as well as to establish a comprehensive understanding of patients in clinical work.

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